

F2 - Taking Action Against the Leading Cause of Preventable Birth Defects

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- **All evaluations must be completed by August 31, 2018 in order for CNE to be awarded.**



Taking Action Against a Leading Cause of Preventable Birth Defects

YOU CAN BE PART OF THE SOLUTION!

Speaker Disclosures

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- ▶ Founder and Board of Directors Member, Alaska Center for FASDs
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By the end of this session the learner will be able to:

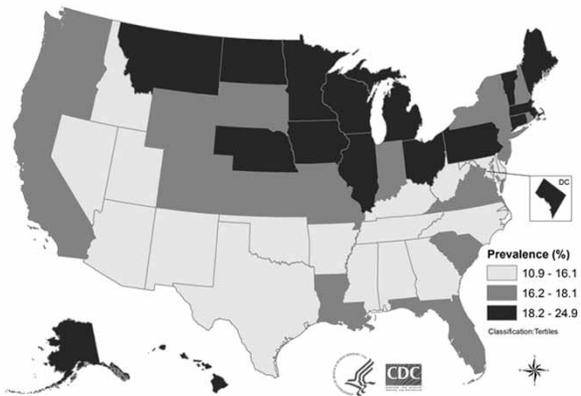
1. Discuss current trends in women's alcohol use and the complexities of addressing alcohol as a physical and behavioral teratogen in our culture
2. Describe the teratogenic impact of alcohol on the fetus and manifestations of FASDs- preventable lifelong disabilities .
3. Apply best practices to support women to prevent alcohol-exposed pregnancies



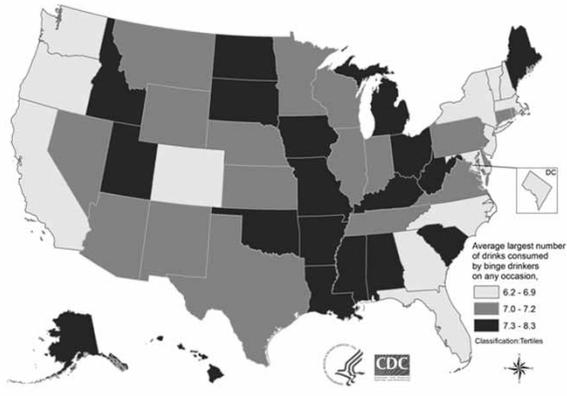
- ▶ Significant role in American history & marketing to women
- ▶ It is the 'social glue' we use for:
 - Celebrations & memorials
 - Sports & social events
 - "Nights out" to relax & socialize
 - Teen 'rites of passage'
 - Self-medication when it is too difficult or expensive to access mental health services

Binge Drinking Patterns Among U.S. Adults, 2015

Prevalence



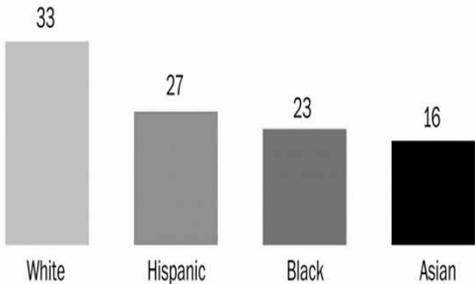
Intensity



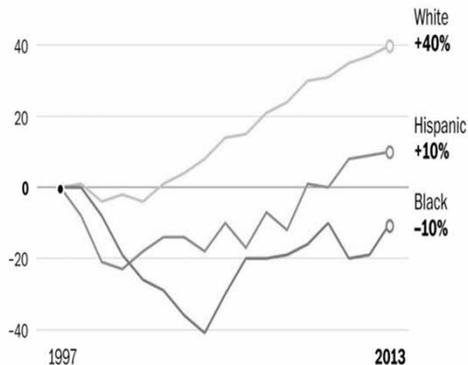
www.cdc.gov/alcohol/data-stats.htm

Women's alcohol use is increasing, especially among white women.

Percentage of women who binge drink



Percentage change of women who binge drink



Kerr, Mulia & Zemore, 2014

Concerning trends



High unintended pregnancy rates
 +
 High numbers of binge drinking and continued drinking in pregnancy
 +
 Providers missing opportunities to talk about the risks
 =
 Increased risk of *rising* numbers of people with fetal alcohol spectrum disorders (FASDs) in the U.S.

Photos courtesy of the University of Louisville FASD Clinic-Weisskopf Center, Child Evaluation Center and the FASD Southeast Regional Training Center www.FASDsoutheast.org



Fetal Alcohol Spectrum Disorders (FASDs)



Alcohol is a potent physical and behavioral teratogen influenced by many variables.

Effects cannot be reliably predicted for any given mother/baby pair.



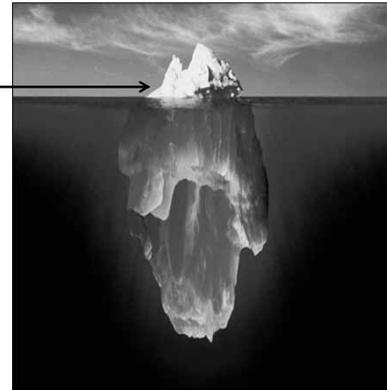
FASD: 1 in 20



FASDs present along a continuum

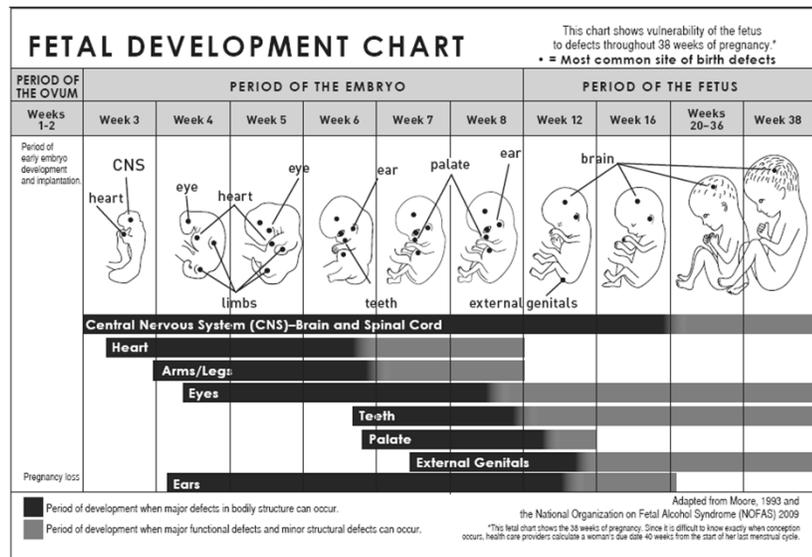
► Behavioral, cognitive, neurological, and physical symptoms

- Fetal alcohol syndrome (FAS)
- Partial fetal alcohol syndrome (pFAS)
- Alcohol related neurodevelopmental disorder (ARND)
- Alcohol related birth defects (ARBD)
- Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)



Effects of alcohol are highly individualized

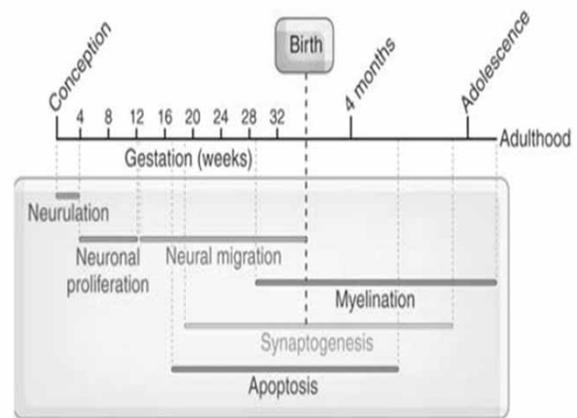
- Genetic differences
- Windows of development
- Timing of exposure
- Dose
- Maternal and fetal co-factors



https://www.cdc.gov/ncbddd/fasd/documents/fasdbrochure_final.pdf

Studies show alcohol mainly targets the brain

- Alters neurogenesis and migration of neurons
- Increases neuronal cell death and/or apoptosis
- Alters dendritic growth, resulting in loss of functionality
- Alters microvascular development and induces hypoxia and/or ischemia
- Decreases protein synthesis
- Enhances free radical toxicity, resulting in premature cell death
- Impairs **DNA methylation**
- Causes vasoconstriction within the placenta, umbilical arteries/vein



Riley & McGee, 2005

Multigenerational epigenetic impact?

- ▶ July 2017 UC Riverside study (Abbott, et al.)
 - ▶ Effects of prenatal ethanol exposure in mice over several generations
 - ▶ Impacts on offspring anatomy of neocortex, abnormal motor behavior, increased anxiety
 - ▶ First generation offspring showed atypical gene expression, abnormal development of neural network in neocortex, behavioral deficits
 - ▶ All three generations had significant reductions in body weight and brain size
 - ▶ Unexposed 2nd and 3rd generations had the same brain impact even without the direct ETOH exposure

So what is epigenetics???

- ▶ DNA modifications that do not change the DNA sequence can affect gene activity
- ▶ Chemical compounds that are added to single genes can regulate their activity; these modifications are known as **epigenetic** changes



What about Dad?

- ▶ Paternal influences can cause birth defects via epigenetic mechanisms such as DNA methylation, histone medication & miRNA expression
- ▶ Interplay between maternal and paternal effects *needs to be studied*

BOTTOM LINE

- ▶ **His alcohol use can lead to *FASD* (not *FAS*) in his offspring, as well as, may cause deficiencies in organ weights in his children**
- ▶ Studies imply that early changes in the father's lifestyle can decrease prevalence of congenital disorders in his offspring

How much alcohol is 'safe'?

- ▶ Fetus has little to no ability to metabolize alcohol
 - ▶ Placenta is a 'sieve' & fetal level may be higher than mother's
 - ▶ Relies on mother to remove alcohol from system
 - ▶ Accumulates in amniotic fluid (where fetus is re-exposed)
- ▶ Binge pattern known to be the worst
- ▶ Unpredictable outcome with 'light to moderate drinking' patterns
 - ▶ May not follow a simple linear dose/response pattern

Common 'Domains' of Impairment

- ▶ **Communication:** expressive, receptive, articulation, social/pragmatic language
- ▶ **Sensory** integration
- ▶ **Visual** perception/motor integration
- ▶ **Fine or gross motor**
- ▶ **Attention/Hyperactivity**
- ▶ **Learning & Memory**
- ▶ **Executive function:** challenges in planning/prioritizing, organizing, task initiating, shifting, impulse control, emotional control, flexible thinking, working memory, self-monitoring
- ▶ **Adaptive Living:** difficulties with functional academics, self-direction, social skills, community use, health & safety, self-care routines

Recognition challenge

- ▶ Pediatric professionals have limited access to the maternal prenatal alcohol exposure (PAE) information
- ▶ **Many individuals get *multiple diagnoses* but NOT the one for the underlying organic brain damage from prenatal alcohol exposure (PAE)**
- ▶ Obstetrical providers can help by using ICD-10 codes in **prenatal problem risk lists** and by supporting the process to have this risk information transferred to newborn records

ICD-10 Codes for Maternal Record

099.310 Alcohol use complicating pregnancy, unspecified trimester
 099.311 Alcohol use complicating pregnancy, first trimester
 099.312 Alcohol use complicating pregnancy, second trimester
 099.313 Alcohol use complicating pregnancy, third trimester
 099.314 Alcohol use complicating childbirth

ICD-10 Codes for Newborn Record

P04.3 Newborn affected by maternal use of alcohol
 Q86.0 Fetal alcohol syndrome (dysmorphic)

Correct diagnosis makes a difference...

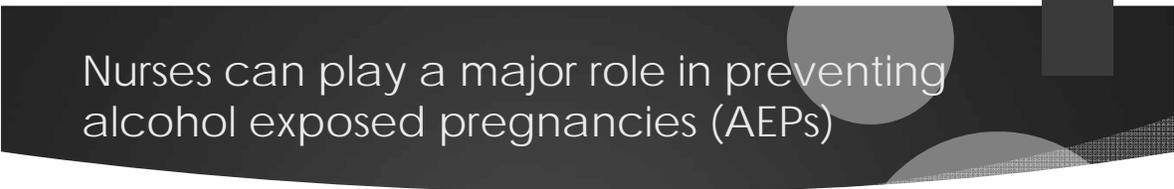
"Things are going reasonably well with my son who was diagnosed with static encephalopathy (ARND) a few years ago. He will be a senior in high school next year and is hoping to attend a community college (and play baseball) after he graduates.

I honestly believe that getting the diagnosis made a big difference **in our figuring out how to parent him** and in his being successful in high school."



Having the
conversation

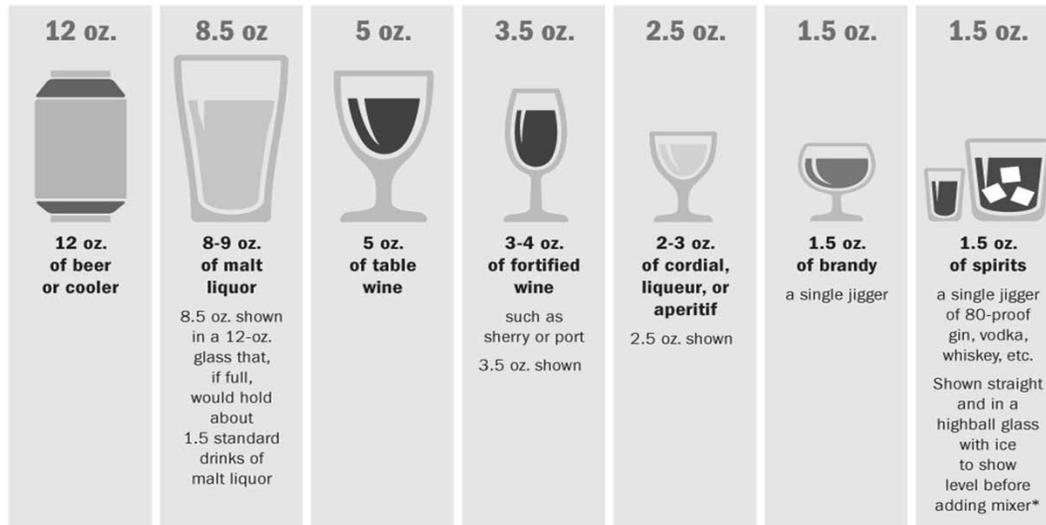
WHAT DO I
SAY?!?!?



Nurses can play a major role in preventing
alcohol exposed pregnancies (AEPs)

- ▶ Routinely **screen all women** for alcohol use
- ▶ Develop & practice key phrases for brief interventions
- ▶ Help **all women** understand that **alcohol is a teratogen...** We **don't know any safe amount of a teratogen** during pregnancy
- ▶ Explore the importance of alcohol in her social/personal life to gain insight & ideas for your brief intervention

Standard drink sizes



Centers for Disease Control and Prevention. *Planning and Implementing Screening and Brief Intervention for Risky Alcohol Use: A Step-by-Step Guide for Primary Care Practices*. Atlanta, Georgia: Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, 2014.



Recommended alcohol consumption limits

	Single Occasion*	Single Day	Single Week
Healthy women (ages 21+ years, no medication)	No more than 3 drinks	No more than 1 drink	No more than 7 drinks
Women who are pregnant or may become pregnant	No amount or type is considered safe to consume at any time		

Alcohol limits can be affected by prescriptions, over-the-counter medications, and some existing medical conditions.

*A single occasion is estimated as a 2 hour period.

AUDIT (U.S.): Alcohol Use Disorders Identification Test

Instructions: Alcohol can affect your health, medications, and treatments, so we ask patients the following questions. Your answers will remain confidential. Place an X in one box to answer each question. Think about your drinking in the past year. A drink = one beer, one small glass of wine (5 oz.), or one mixed drink that contains one shot (1.5 oz.) of spirits.

Questions	0	1	2	3	4	5	6	Score
1. How often do you have a drink containing alcohol?	Never	Less than monthly	Monthly	Weekly	2-3 times a week	4-6 times a week	Daily	
2. How many drinks containing alcohol do you have on a typical day when you are drinking?	1	2	3	4	5-6	7-9	10 or more	
3. How often do you have X or more drinks on one occasion? (5 for men under age 65; 4 men aged 65 or older and all women)	Never	Less than monthly	Monthly	Weekly	2-3 times a week	4-6 times a week	Daily	
								TOTAL (1-3)
4. How often during the last year have you found that you were not able to stop drinking once you started?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily			
5. How often during the last year have you failed to do what was normally expected of you because of drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily			
6. How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily			
7. How often during the last year have you had a feeling of guilt or remorse after drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily			
8. How often during the last year have you been unable to remember what happened the night before because of your drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily			
9. Have you or someone else been injured because of your drinking?	No		Yes, but not in the last year		Yes, during the last year			
10. Has a relative, friend, doctor, or other health care worker been concerned about your drinking or suggested you cut down?	No		Yes, but not in the last year		Yes, during the last year			
Babor, Higgins-Biddle, Saunders, & Monteiro, 2001								TOTAL (1-10)

Stigma gets in the way...

Stigma contributes to decisions about discussing alcohol use, especially during pregnancy.

Stigma increases patient fears of being judged or devalued by others, especially a healthcare provider.

A recurring theme in my practice...

"It still blows my mind that of all the professionals we went to for help with our son, starting at age 6, no one mentioned FASDs as something to consider until a school psychologist sat in on a meeting about his behavior in 7th grade. I'd love to help others avoid that type of delay in recognition and intervention."

- ▶ NURSES CAN BE LEADERS TO HELP CHANGE THIS STORY!

Reasons women/girls may drink during pregnancy:

- ▶ Unaware they are pregnant
- ▶ In denial because they do not want to be pregnant
- ▶ Uninformed about the risks for an embryo/fetus
- ▶ Underestimate the risk because they know someone who drank during pregnancy and "their children are fine"
- ▶ Alcohol use is the norm in their social group & abstaining may be difficult
- ▶ Using it to cope with violence, depression, poverty, or isolation
- ▶ May be struggling with addiction

How much alcohol is 'safe'?

- ▶ Fetus has little to no ability to metabolize alcohol
 - ▶ Placenta is a 'sieve': fetal level may be higher than mother's
 - ▶ Relies on mother to remove alcohol from system
- ▶ Alcohol can accumulate in amniotic fluid (where fetus is re-exposed) before it passes back to the mother
- ▶ Mom's metabolism effected by her nutrition, genetics, body weight
- ▶ Dose matters – binge pattern the worst: unpredictable outcome even with 'light to moderate drinking' patterns (& it may not follow a simple linear dose/response pattern)
- ▶ Timing matters: one glass of wine for a 36 week fetus is quite different than at 8 weeks but neither is considered a safe time to imbibe

Findings in children

- ▶ Low dose levels are associated with behavioral effects in 6 year olds
- ▶ Achenbach Child Behavior Checklist: children with any prenatal alcohol exposure are 3x more likely to exhibit "rule-breaking" behaviors
- ▶ Executive function & adaptive living areas - these are often most impacted and reveal themselves over time (often not until early adolescence)
- ▶ May have studied executive function at too young an age (e.g., 5)

She is currently pregnant... How to respond?

- ▶ "I am continuing to have a glass of wine a few nights a week, that's okay right?"
- ▶ "I want to drink champagne at my best friend's wedding ... that should not be a problem since I'll be in the third trimester."
- ▶ "I'll really miss going out with my friends for our 'end of the work week' drinks. Can I go just once a month or so?"

Remind women who might want to drink during pregnancy...

- ▶ **No type is safe** – beer, wine, liquor, wine coolers, homebrew, etc.
- ▶ **No way to predict** if she would be the mother/baby pair with more or less impact from the alcohol
- ▶ **Fetal brain is the main target** – for the entire nine months
- ▶ Potential for multigenerational impacts due to possible **epigenetic influence**

What can we tell women to do?



- ▶ If she screened 'at-risk': explore ideas to reduce volume when drinking
- ▶ If she is attempting to get pregnant, not using birth control and does not choose to stop drinking: track her cycle & time her alcohol use
- ▶ If she is pregnant and wants to drink: suggest alternatives

Unpublished. Developed through CDC Cooperative agreements 1U01DD001143, 1U01DD001144, 1U84DD001135

Intervention Considerations: One Key Question®

Home - Clinicians - Effective Contraceptive Use Metric - OKQ Materials - Media - Ask Yourself OKQ - Donate

One Key Question®
"Would You Like to Become Pregnant in the Next Year?"



The One Key Question® Initiative (OKQ) is the Oregon Foundation for Reproductive Health's groundbreaking, yet simple, solution to making Oregon women and families healthier and ensure that more pregnancies are wanted, planned, and as healthy as possible. OKQ encourages all primary care providers to routinely ask women about their reproductive health needs and has been endorsed by 30 professional organizations and associations across Oregon and the country.

By asking women "Would you like to become pregnant in the next year?" primary care clinicians can more fully support women's preventive reproductive health needs, such as preventing an unintended pregnancy or preparing for a healthy pregnancy.

Contact us for more information- info@onekeyquestion.org

Oregon Foundation for Reproductive Health: www.onekeyquestion.org/

Mother Baby & Pediatric Nurses can play a key role

- ▶ Neonates prenatally exposed to alcohol may have neurobehavioral symptoms
 - ▶ Hyper- or hypotonia, facial hypotonia & dysmature swallowing, tremors, hyper-or hypo-reflexia, irritability, auditory sensitivity, poor visual tracking, irregular sleep patterns, (rarely)seizures
(source: Dr. Ira Chasnoff-NII Upstream webinar NAS versus Withdrawal 2018)
- ▶ Provide anticipatory guidance about importance of standardized developmental screening
 - ▶ Programs such as Help Me Grow (uses ASQ tool-online) and
 - ▶ Sharing alcohol exposure story with the pediatric provider
- ▶ Discharge education related to Safe Sleep is important
 - ▶ Infants with perinatal alcohol exposure have an increased risk for SIDS
 - ▶ Bed sharing risk for infant is increased if mother is impaired (via substance/alcohol/tobacco use)

Rochelle's Story

- ▶ 21 year old pregnant with her 4th child
- ▶ Child protection had removed all of her previous children
- ▶ Different fathers for each child, none involved with her long term
- ▶ Short stature, + facial features, evidence of brain-based differences in her behaviors (poor memory, poor executive function, adaptive living skills marginal)+ 'survivor mode living' pattern
- ▶ Trauma history –her mother had alcoholism & was abusive (emotional, physical, sexual), displacement
- ▶ Disrupted educational experiences
- ▶ Self-medicating with tobacco, alcohol, occasional substances

Tips for working with women/girls who may have an FASD...

- ▶ Try to 'reach them where they are at', i.e. figure out what they might 'know'/believe
- ▶ Be **concrete and concise** in verbal messages
- ▶ Check for understanding (have them tell you what they heard)
- ▶ Provide **visual cues** to help them understand and remember what you said
- ▶ **Limit choices** to two or three at a time – they cannot manage 'load'
- ▶ Use '**external brain cues**' to help them stay on track.... Help them put appointments in their phone with reminder cues, etc.
- ▶ Be non-judgmental (even when they mess up)
- ▶ **Repeat, repeat, repeat**... They may need repetition to master and/or remember things
- ▶ User-independent contraceptive methods recommended (due to executive function deficits)

Be a champion for preventing AEPs

- ▶ Nurses are *trusted* front line professionals who can help with prevention & early recognition/intervention of FASDs
- ▶ Obligation to share this information, be honest with those we care for
- ▶ Continue message of no safe time, type, or amount of alcohol
- ▶ Share no safe teratogen in pregnancy, that alcohol is a powerful physical and behavioral teratogen... Alcohol is an 'intrauterine environmental pollutant'
- ▶ In our homes, our clinic/hospitals, and in our communities we have an opportunity to make an important contribution that can change lives long term

Sage words for nurses from an RN parenting a child w/FASD

- ▶ No mother purposely harms her child.
- ▶ FASD is a frightening diagnosis with so many unknowns.
- ▶ Parenting a child with FASD is difficult and sometimes goes against the typical parenting advice. Do not assume you know what works best for someone else's child.
- ▶ Our children are beautiful and full of misunderstood energy.
- ▶ Parents love to hear positive things about their children. Let them know that you see the good in their children.

Training and Resources

- ▶ Collaborative for Alcohol-Free Pregnancy: Partnering for Practice Change
nccd.cdc.gov/FASD/ online courses for nurses & other professionals
- ▶ NPWH short webinars – *Optimizing Preconception Health: Preventing Unintended Teratogen Exposure in Reproductive Age Women*
www.npwh.org/courses/curriculum/details/903
- ▶ National Organization on Fetal Alcohol Syndrome (NOFAS)
www.nofas.org/ birth mother support, great information re: individuals living with FASD

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